Objective

• To analyze reporting of the Delphi method to achieve consensus on diagnosis and management guidelines in rare diseases.

Background

• The Delphi method is a structured process, widely used to achieve expert consensus during the development of guidelines for decision-making in clinical practice.
• While the methodological quality of practice guidelines is often assessed using the Appraisal of Guidelines for Research and Evaluation (AGREE) Reporting Checklist, there is currently a lack of standardised reporting requirements for Delphi methods. An e-Delphi checklist is currently in development.
• Here, the use of the Delphi technique to achieve consensus on guidelines in rare diseases has been analysed.

Methods

A pragmatic literature review was conducted in September 2017 by simultaneously searching Embase and MEDLINE® databases via the OvidSP platform.

• The search terms used related to rare diseases, practice guidelines and Delphi methodology (Figure 1). No date limit was applied.

Results

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• To analyse reporting of the Delphi method to achieve consensus on diagnosis and management guidelines in rare diseases.

Research Design and methods

A pragmatic literature review was conducted in September 2017 by searching Embase and MEDLINE® databases. Publications were screened by a single reviewer to include English language articles in which the Delphi method was used for the development of guidelines in rare diseases, well-designed Delphi studies present a valuable tool to establish consensus and develop relevant clinical guidelines.

• Improved reporting of Delphi methods in publications is necessary, with the majority of identified studies lacking AGREE-recommended detail.

Conclusions

Of greatest importance, agreement thresholds were not reported for 10/11 (91%) studies and the consensus threshold was not reported for 5/11 (45%) studies.

• The reported methods of delivering the results to the panelists were via email, face-to-face or a combination of both. However, 3/11 (27%) studies did not report the method of delivery used.

• The collection and circulation of panelist feedback, which was not reported in 3/11 (27%) studies, was used to inform subsequent Delphi stages, which were not reported by 5/11 (45%) and 7/11 (64%) studies respectively.

• Only 7/11 (64%) reported the number of statements assessed.

Conclusions

• Since data from randomised controlled trials are scarce in rare diseases, well-designed Delphi studies present a valuable tool to establish consensus and develop relevant clinical guidelines.

• Improved reporting of Delphi methods in publications is necessary, with the majority of identified studies lacking AGREE-recommended detail.

• To improve reporting of Delphi-based consensus guidelines for rare diseases, publication should be carried out in line with existing and newly developed best practice recommendations for reporting Delphi methods.

Literature Review

• Searches identified 25 results, which were published between 2009–2017.
• 12 records fulfilled the inclusion criteria, which reported on 11 unique Delphi studies (Figure 2).

Reporting of the Delphi Method (Figure 3)

• Literature searches guided the development of statements for Delphi panel review in 9/11 (73%) studies, but only 2/11 (18%) conducted systematic literature reviews.

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References


Author Contributions

Substantial contributions to study conception/design, or acquisition/analysis/interpretation of data: HRP, SJG, AG, DS. Drafting of the publication, or revising it critically for important intellectual content: HRP, SJG, AG, DS. Final approval of the version published: HRP, SJG, AG, DS.

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Table 1: Summary of the rare diseases investigated within the identified publications

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number of studies</th>
<th>Type of guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orphan-classified rare diseases</td>
<td>9</td>
<td>Management</td>
</tr>
<tr>
<td>Non orphan diseases</td>
<td>2</td>
<td>Management</td>
</tr>
<tr>
<td>Delphi techniques used</td>
<td>5</td>
<td>Management</td>
</tr>
</tbody>
</table>

Figure 2: PRISMA diagram

Figure 3: Reporting of the Delphi method

Graphical abstract

Abstract

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